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DATE: October 19, 2004

TO: INTERESTED PARTIES

SUBJECT: STUDY OF DEATHS THAT OCCURRED IN 1999

Enclosed for your information is "Causes and Contributing Factors: Mortality of Individuals with Developmental Disabilities, A Study of Deaths that Occurred in 1999" (1999 Cohort Study). The report was produced by California State University, Sacramento (CSUS) Division of Nursing, in collaboration with the Department of Developmental Services (DDS) and regional center staff. The study was initiated in 2000 and completed in 2003.

The 1999 Cohort Study concentrated on how health outcomes were influenced by the quality of care provided by physicians and residential care providers, and by choices made by consumers and their families. This study focused solely on the community care setting and concentrated on the quality of health care and its impact on mortality.

There were two main findings in the 1999 Cohort Study. The first was that the quality of health care in the community continues to present challenges, although this study found that improvements in the quality of health care had been made since the 1994 Cohort Study.

The second finding was that there were proportionately fewer individuals noted to have problems with physician and residential staff management of their ongoing health problems. However, the quality of health care, including supervision and treatment, continued to be an issue for some individuals who reside in out-of-home settings.

Many of the drawbacks noted in the 1994 Cohort Study were resolved in the 1999 Cohort Study. These included:

- The data collection tool was refined for the 1999 Cohort Study, and allowed for more specific data collection regarding preventive health and health conditions than the tool utilized in the 1994 Cohort Study.

- Medical experts were clinicians from the regional centers and were able to discuss findings as a group. Dialogue permitted complete agreement among the physician-nurse teams; problems identified were straightforward variations from expected practices. The expert panel of clinicians in the 1999 Cohort Study made viable recommendations based on their findings and their unique understanding of the regional center system.

Although many of the drawbacks were resolved from the 1994 Cohort Study, there were some drawbacks that remained. These included:

- The data collection tool for preventive health was revised for the 1999 Cohort Study, which limited the longitudinal aspects of the study.

- The contractor reported that the study had difficulty gaining access to the individual's medical record. The study relied on the information in the regional center record, the residential file and any other information made available. The regional center, with its mission as a special service agency, does not provide primary health care and therefore does not have those medical records.

Recommendations made in the Cohort Study included the following:

- Promote preventive health education and assessments for individuals with developmental disabilities.

- Develop a "Quick Reference Guide" for community physicians on managing conditions commonly found in the regional center population. This reference guide should include guidelines for ongoing medical management of specific conditions; information on the types of specialists needed by consumers with these conditions, as well as criteria for when referrals should occur; guidelines for medication management of common conditions, including monitoring drugs; and criteria for when regional center case managers and residential facilities need to call in a regional center physician or nurse for consultation.

In response to these recommendations, DDS has taken the following actions:

- Developed on-line resources (www.ddhealthinfo.org and www.ddssafety.net) which provide information for physicians, regional center clinicians, service providers, parents and consumers, including "Medical Management

Considerations" for thirty-five selected conditions associated with developmental disabilities. These are delineated by age, medications, specific influencing factors and psychosocial considerations.

- Included in the annual Physician Training program, information on the types of specialists needed by consumers with complicated medical conditions.

- Produced, in collaboration with the California Board of Pharmacy, *Health Notes: Care of Children & Adults with Developmental Disabilities.*

- Contracted with an Independent Risk Management Contractor. One major activity of the Contractor is to complete bi-annual mortality reviews for consumers living in the community. This Contractor also provides annual training to the regional centers on risk management and mitigation, and is available to regional centers for technical assistance.

- Instituted Direct Support Professional (DSP) staff training as a requirement for all community care facilities. This training includes:

    - Risk Management and Incident Reporting;
    - Medication Management;
    - Wellness: Maintaining the Best Possible Health;
    - Signs and Symptoms of Illness and Injury;
    - Risk Management: Environmental Safety;
    - Preventive Health Care and Advocacy; and
    - Nutrition and Exercise.

- Continued Healthcare Professional trainings for medical providers in the community. To date, 34 trainings have been conducted with approximately 3,500 healthcare professionals trained in the complexities of the care and treatment of persons with developmental disabilities.

- Published the *Wellness Digest*, which provides information on specific health issues.

- Issued regulations requiring each regional center to maintain a risk management plan.

- Established a plan for developing "Best Practice Guidelines" for regional centers to improve the accuracy and completeness of regional center medical records.

DDS continues to pursue improvements as recommended not only by this study, but as a result of many reports and recommendations from numerous sources. Strong emphasis is currently focused on health promotion, screening tests, and increased quality management and accountability systems of health care services. In addition, we continue to support the Wellness Initiative and collaborative partnerships to promote quality health care services for all Californians with developmental disabilities.

Please contact Jo Ellen Fletcher, Chief of DDS's Health and Wellness Section, at (916) 654-2133 if you have any questions regarding this study.

Cordially,

Original Signed By
CLIFF ALLENBY
Director

Enclosure

Causes and Contributing Factors:

Mortality of Individuals with Developmental Disabilities

A Study of Deaths that Occurred in 1999

NOTE: Some information directly related to a specific consumer(s) was deleted to ensure confidentiality pursuant to Welfare and Institutions Code section 4514.

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ACKNOWLEDGEMENTS

This study would not have been possible without the generous cooperation of staff working in California's 21 Regional Centers. They provided access to consumer's files and space for researchers to abstract data. They also assisted researchers in locating residential facilities and in eliciting their cooperation with the study. We are also very grateful to the residential facilities and their staffs who also cooperated with this study.

We are especially indebted to the physicians and nurses who served as members of the expert panel. They generously donated their time to evaluate consumer records, as well as offer constructive feedback on needed changes to the system of care for individuals with developmental disabilities. They were an outstanding group of experts who were very professional and delightful to work with. Many thanks to the members of the expert panel, who are listed below:

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We would also like to thank Judi Angell, Paul Choate and Marjorie Mor Lui for all of their assistance.

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PURPOSE OF THE STUDY

This study explored the influence of health-related services on the morbidity and mortality of a randomly selected sample of individuals with developmental disabilities who died in the first half of 1999. California Department of Developmental Services commissioned California State University, Sacramento Division of Nursing, to examine the quality of health and residential care provided to these persons, all of whom lived in out-of-home residential facilities. This study was a follow-up to previous work that evaluated deaths that occurred in 1994. The focus of this study was to determine how health outcomes were influenced by the quality of care provided by physicians and residential care providers, and by choices made by consumers and their families. Another goal of this study was to identify trends and patterns in services that may adversely influence health outcomes. Findings were compared with those of the 1994 study.

RESEARCH QUESTIONS

1. Did the quality of health care services provided by the community health care delivery system (including physicians and health insurers) contribute to the morbidity and/or mortality of individuals studied?
2. Did the quality of health care and supervision provided by residential staffs contribute to the morbidity and/or mortality of individuals studied?
3. Did the consumer's or family member's wishes contribute to morbidity or mortality?
4. Did the consumer engage in criminal activity that contributed to the death?

STUDY DESIGN AND METHODOLOGY

A random sample was drawn from those persons with developmental disabilities who died in the first half of 1999 while residing in out-of-home settings. Extensive data were gathered on the delivery of health-related services for the sample using a standardized data collection protocol. Using this protocol, in-depth data were gathered from Regional Center and client facility records. The protocol, a revised version of the 1994 protocol, was programmed so that most of the abstracted data were linked to a

database. In addition, drop-down menus were created for many items, such as type of residence and type of health problem, to ensure a standardized documentation format. All health problems were linked to ICD-9 codes. The following areas were addressed:

- Preventive health care, including screenings and exams;
- Ongoing medical care;
- Access to specialty care;
- Health Insurance Restrictions;
- Residential supervision and care usually provided to the consumer;
- Emergency response before the death;
- Consumer and family wishes and compliance concerning health care, including Advanced Care Directives;
- Other aspects of care that may have influenced the occurrence or timing of the death.

In addition the Department of Developmental Services (DDS) provided other data on each person that included the Client Development Evaluation Report (CDER) data, Bureau of Vital Statistics records on death, and Special Incident Reports.

Registered nurses were hired and trained to abstract data using the data abstraction instrument. Each nurse was screened on her ability to abstract data comprehensively and accurately using a test client record. Nurses were then sent into the field and further evaluated on their ability to accurately and efficiently abstract client health care data by their supervisors. Nurses were all provided lap top computers to aid in the data abstraction process and trained on use of the instrument.

Data were gathered from all available records on clients, including regional center records, residential care facility records, and hospital records as appropriate. The registered nurses were also given copies of CDER reports, death certificates, and Special Incident Reports. Regional center staff helped identify facilities, assisted with access to resistant facilities, and helped locate files from facilities that had moved or closed. All completed records were reviewed and edited by a supervising research nurse. All identifying information was removed from the abstracted records.

A panel of California physicians and nurses who are experts in the care of individuals with developmental disabilities was formed by DDS to review and rate a sample of records using an instrument that rated the quality of the following:

- Preventive screening exams and assessments
- Ongoing medical management of the consumer's health
- Influence of insurance restrictions on consumer morbidity
- Residential care management of the consumer's health, supervision, and safety
- Emergency response near the time of death
- Consumer and family choices

In addition, expert panelists identified and categorized problems as the following:

- Problems with medical care management
- Identifications of additional health services needed
- Problems in residential care and services

(See Appendix for a complete copy of the expert panel rating form.)

Six nurse and physician teams were created, and each team rated 10 cases. Each person reviewed and rated each case independently. They then compared their answers, resolved any differences of opinion, and developed a final rating of each case. The expert panelists reviewed a randomly selected sample of 60 cases; two members of the expert panel reviewed and rated the remainder of the records. Inter-rater reliability was established at greater than 85% between the two reviewers and reviews by the expert panelists.

When the reviews were completed, the expert panelists discussed their findings as a group. The expert panelists identified qualitative differences in care, and made recommendations for changes in services, including issues related to type of residential setting. Experts in the fields of medicine, nursing, and statistics worked together to develop the analyses and make recommendations for improvement in services.

STATISTICAL METHODS

All available data from computerized databases, field data collection, and the expert panel reviews were analyzed statistically. This included both descriptive and comparative analyses. Expert panelists rated the quality of health care of each client record. The ratings addressed Special Care Directives, Emergency Response, Services

Provided by Physicians, Services Provided by Residential Care Providers, and individual and family choices.

Statistical analyses utilized the Mann-Whitney test to obtain p-values for comparing quality ratings at different residential settings. These summarize the strength of evidence against differences in quality ratings being explainable as random flukes. The Mann-Whitney test depends only on the ordering of the ratings and does not assume that they follow a normal distribution.

Sample Selection & Description

The goal was to have a random sample of 200 persons who had been living in an out-of-home setting at the time of their deaths during the first half of 1999. The Department over-sampled, randomly selecting 222 cases, because past experience demonstrated that some records would not be available due to loss, and some facilities would not cooperate with the study. Of the 222 cases selected, only 166 met the criteria for inclusion in this study (see Table 1 below).

Table 1: Description of 222 Cases Randomly Selected For The Study

Lived in Out of Home Residential Setting— Met Study Criteria	
Regional Center and Facility Records Available for Review	166
Regional Center Records Not Available (Lost or destroyed, involved in litigation, court protected)	12
Facility Refused Access, Regional Center Record Data Too Limited To Use	8
Death Occurred Before 1999	7
Resided In Independent/Supported Living or At Home— Did Not Meet Study Criteria	29
Total	**222**

As can be seen in Table 2, the sample selected is somewhat older than those not selected (statistically significant for ages 31 to 50). There were proportionately more females in the sample than in the general population living in out-of-home settings, and the sample contained slightly fewer African-American and Hispanic consumers, but the differences were not statistically significant.

Table 2: Age, Gender and Race/Ethnicity of Total Deaths by Sample Selection and Placement

	Out-of –home						Home		Other	
	In Sample		Not in Sample		Total					
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Age Group										
<11	16	9.6	53	9.2	69	9.3	312	49.3	0	0.0
11-20	5	3.0	33	5.8	38	5.1	86	13.6	1	1.3
21-30	11	6.6	36	6.3	47	6.4	61	9.6	8	10.3
31-50	60	36.2	150	26.2	210	28.4	69	10.9	36	46.1
51-70	43	25.9	173	30.2	216	29.2	25	4.0	27	34.6
>70	26	15.7	82	14.3	108	14.6	7	1.1	5	6.4
Unknown	5	3.0	46	8.0	51	6.9	73	11.5	1	1.3
Total	166	100.0	573	100.0	739	99.9	633	100.0	78	100.0
Gender										
Male	82	49.4	298	52.0	380	51.4	348	55.0	45	57.7
Female	84	50.6	275	48.0	359	48.6	285	45.0	33	42.31
Total	166	100.0	573	100.0	739	100.0	633	100.0	78	100.0
Race/Ethnicity										
Hispanic	19	11.5	83	14.5	102	13.8	194	30.7	5	6.4
White	122	73.5	401	70.0	523	70.8	206	32.5	59	75.6
Black	8	4.8	48	8.4	56	7.6	67	10.6	8	10.3
Other	9	5.4	26	4.5	35	4.7	81	12.8	5	6.4
Unknown	8	4.8	15	2.6	23	3.1	85	13.4	1	1.3
Total	166	100.0	573	100.0	739	100.0	633	100.0	78	100.0

Note: Distribution based on CDER data.
X^2 $p \leq .05$

Developmental characteristics of individuals who died are displayed in Table 3. Distributions between those living in out-of-home settings in the sample are similar to those not in the sample.

Table 3: Developmental Characteristics of Total Deaths by Sample Selection and Placement for Consumers With CDER Files

	Out-of Home						Home		Other	
	In Sample		Not in Sample		Total					
	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Cerebral Palsy										
No	97	61.8	344	64.2	441	63.6	228	58.9	64	82.0
Yes	60	38.2	192	35.8	252	36.4	159	41.1	14	18.0
Total	157	100.0	536	100.0	693	100.0	387	100.0	78	100.0
Seizures										
None	88	56.1	317	59.1	405	58.4	238	61.5	54	69.2
Partial	6	3.8	12	2.2	18	2.6	16	4.1	4	5.1
Generalized	30	19.1	119	22.2	149	21.5	60	15.5	13	16.7
Other	33	21.0	88	16.4	121	17.5	73	18.9	7	9.0
Total	157	100.0	536	99.9	693	100.0	387	100.0	78	100.0
Mental Retardation										
None	14	8.9	17	3.2	31	4.5	50	12.9	20	25.6
Mild	34	21.7	118	22.0	152	21.9	91	23.5	45	57.7
Moderate	27	17.2	108	20.15	135	19.5	80	20.7	10	12.8
Severe	28	17.8	100	18.7	128	18.5	71	18.4	1	1.3
Profound	52	33.1	177	33.0	229	33.0	56	14.4	2	2.6
Unspecified	2	1.3	16	2.3	18	2.6	39	10.1	0	0.0
Total	157	100.0	536	100.0	693	100.0	387	100.0	78	100.0
Ambulation										
Yes	61	38.85	213	39.7	274	39.5	164	42.4	60	76.9
No	96	61.15	323	60.3	419	60.46	223	57.6	18	23.1
Total	157	100.0	536	100.0	693	100.0	387	100.0	78	100.0
*Self-care Ability Levels										
0-25 (low)	58	36.9	193	36.0	251	36.2	183	47.3	2	2.6
26-50	22	14.0	87	16.2	109	15.7	37	9.6	4	5.1
51-75	37	23.6	102	19.0	139	20.1	38	9.8	5	6.4
76-100 (high)	40	25.5	154	28.7	194	28.0	129	33.3	67	85.9
Total	157	100.0	536	99.9	693	100.0	387	100.0	78	100.0
Developmental Levels										
0-25 (low)	21	13.4	63	11.75	84	12.1	48	12.4	0	0.0
26-50	53	33.8	207	38.6	260	37.5	154	39.8	3	3.8
51-75	56	35.7	176	32.8	232	33.5	101	26.1	7	9.0
76-100 (high)	27	17.2	90	16.8	117	16.9	84	21.7	68	87.2
Total	157	100.0	536	100.0	693	100.0	387	100.0	78	100.0

Note: Distribution is based on CDER data

The random selection of the sample resulted in a higher proportion of individuals living in ICFs and a lower proportion of those living in CCFs in the sample than for the out-of-home population as a whole.

Table 4: Death In 1999 For Those In Out-Of-Home Placements By Type Of Residence

Residence	In sample		Not in sample		Total	
	Number	Percent	Number	Percent	Number	Percent
Acute/general hospital	4	2.4	7	1.3	11	1.6
Developmental Center	17	10.2	64	11.9	81	11.5
CCF	49	29.5	193	36.0	242	34.5
ICF	41	24.7	106	19.8	147	20.9
SNF	47	28.3	145	27.1	192	27.3
Other	8	4.8	21	3.9	29	4.1
Total	166	99.9	536	100.0	702	99.9

Note: Distribution by living arrangement based on CDER data.
Percents may not total 100% due to rounding.

Demographic characteristics of the sample by type of residence selected for this study are displayed in Table 5.

Table 5: Age, Gender, and Race/Ethnicity of DDS Sample by Type of Residence

	DC		SNF		ICF		CCF		Other CLA	
	Number	**Percent**	**Number**	**Percent**	**Number**	**Percent**	**Number**	**Percent**	**Number**	**Percent**
Age group										
Unknown	0	0.0	1	2.1	2	4.9	2	4.1	0	0.0
00-10	0	0.0	0	0.0	8	19.5	2	4.1	6	50.0
11-20	1	5.9	1	2.1	2	4.9	1	2.0	0	0.0
21-30	3	17.65	2	4.3	1	2.4	5	10.2	0	0.0
31-50	8	47.1	15	31.9	20	48.8	15	30.6	2	16.7
51-70	4	23.5	14	29.8	6	14.6	15	30.6	4	33.3
>70	1	5.9	14	29.8	2	4.9	9	18.4	0	0.0
Total	17	100.0	87	100.0	41	100.0	49	100.0	12	100.0
Gender										
Male	9	52.9	22	46.8	23	56.1	25	51.0	3	25.0
Female	8	47.1	25	53.2	18	43.9	24	49.0	9	75.0
Total	17	100.0	47	100.0	41	100.0	49	100.0	12	100.0
Race/Ethnicity										
Asian	2	11.8	1	2.1	1	2.4	1	2.0	2	16.7
Black	1	5.9	0	0.0	4	9.8	3	6.1	0	0.0
Filipino	1	5.9	0	0.0	0	0.0	0	0.0	0	0.0
Native American	0	0.0	1	2.1	0	0.0	0	0.0	0	0.0
Hispanic	2	11.8	5	10.6	9	22.0	2	4.1	1	8.3
White	11	64.7	39	83.0	24	58.5	41	83.7	7	58.3
Other	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Unknown	0	0.0	1	2.1	3	7.3	2	4.1	2	16.7
Total	17	100.1	47	99.9	41	100.0	49	100.0	12	100.0

Note: Distribution by living arrangements based CDER.
Percents may not total 100% due to rounding.

Predictably, those living in CCFs were higher functioning developmentally than those living in other types of facilities (see Table 6).

Table 6: Developmental Characteristics of DDS Sample by Type of Residence

	DC		SNF		ICF		CCF		Other CLA	
	Number	**Percent**	**Number**	**Percent**	**Number**	**Percent**	**Number**	**Percent**	**Number**	**Percent**
Presence of Cerebral Palsy										
No	3	17.6	32	69.6	16	45.7	41	78.9	5	71.4
Yes	14	82.3	14	30.4	19	54.3	11	21.1	2	28.6
Total	17	99.9	46	100.1	35	100.0	52	100.0	7	100.0
Seizures										
None	8	47.1	32	69.6	12	34.3	31	59.6	5	71.4
Partial	1	5.9	2	4.3	2	5.7	1	1.9	0	0.0
Generalized	7	41.2	5	10.9	11	31.4	7	13.5	0	0.0
Other/Undetermined	1	5.9	7	15.2	10	28.6	13	25.0	2	28.6
Total	17	100.1	46	100.0	35	100.0	52	99.9	7	100.0
Mental Retardation Level										
No Retardation	0	0.0	3	6.5	4	11.4	7	13.5	0	0.0
Mild	0	0.0	9	19.6	4	11.4	17	32.7	4	57.1
Moderate	2	11.7̂	11	23.9	3	8.6	10	19.2	1	14.3
Severe	2	11.8	8	17.4	5	14.3	12	23.1	1	14.3
Profound	13	76.5	15	32.6	17	48.6	6	11.5	1	14.3
Unspecified	0	0.0	0	0.0	2	5.7	0	0.0	0	0.0
Total	17	100.0	46	100.0	35	100.0	52	100.0	7	100.0
Ambulation										
Yes	4	23.5	17	37.0	5	14.3	32	61.5	3	42.9
No	13	76.5	29	63.0	30	85.7	20	38.5	4	57.1
Total	17	100.0	46	100.0	35	100.0	52	100.0	7	100.0
% Selfcare Ability										
0-25 (low)	12	70.6	20	43.5	20	57.1	3	5.8	3	42.9
26-50	3	17.6	8	17.4	5	14.3	5	9.6	1	14.3
51-75	2	11.8	10	21.7	6	17.1	18	34.6	1	14.3
76-100 (high)	0	0.0	8	17.4	4	11.4	26	50.0	2	28.6
Total	17	100.0	46	100.0	35	100.0	52	100.0	7	99.9
% Developmental Levels										
0-25 (low)	5	29.4	7	15.2	8	22.9	1	1.9	0	0.0
26-50	9	52.9	18	39.1	15	42.9	7	13.5	4	57.1
51-75	3	17.7	15	32.6	9	25.7	28	53.8	1	14.3
76-100 (high)	0	0.0	6	13.0	3	8.6	16	30.8	2	28.6
Total	17	100.0	46	99.9	35	100.1	52	100.0	7	100.0

Note: Percents may not total 100% due to rounding. Distributions are based on CDER data.

RESULTS

The majority of deaths (n=126, 76%) were identified as "disease related." Only one of the deaths was classified as a homicide, and two were classified as due to an accident. All three of these consumers resided in Community Care Facilities (CCFs). The majority of those who died did so in acute care hospitals (n=82, 49%). The next most common sites of death were skilled nursing facilities (n=34, 20.5%), followed by the consumers' residences (n=32, 20%). Skilled nursing facilities are expected to provide care for patients who are terminally ill; therefore, the higher rate of deaths in this type of residence is to be expected.

Of the 166 clients, experts identified at least one problem with the quality of care provided to 94 consumers. These problems were classified as related to one or more of the following:

- Preventive screening exams and assessments
- Ongoing medical management
- Residential care management of consumer's health
- Emergency response near the time of death

The experts classified the types of problems for each category using the expert panel coding form.

Research question 1: Did the quality of health care services provided by the community health care delivery system (including physicians and health insurers) contribute to the morbidity of individuals studied?

Preventive Screening Exams and Assessments

Panelists reviewed consumer records and evaulated the preventive health care screening exams and assessments that consumers had received, comparing their findings to national guidelines. As can be noted on Table 7, immunizations, chest x-rays, ECGs, dental exams, PSAs, and sigmoidoscopies were the most likely preventive health care services to be cited as not having been done. Those lacking these preventive health screening measures generally resided in CCFs, ICFs, and SNFs.

Table 7: Preventive Health Screening Exams and Assessments for the 166 Consumers Studied

Preventive Screening Exam/Assessment	Done		Not Done		Not Needed		Unable to Determine		Total	
	#	%	#	%	#	%	#	%	#	%
Height & Weight	118	71.1	42	25.3	2	1.2	4	2.4	166	100.0
Immunizations/Vacccinations	82	49.4	73	44.0	5	3.0	6	3.6	166	100.0
Vision Screening	121	72.9	35	21.1	7	4.2	3	1.8	166	100.0
Hearing Exam	113	68.1	42	25.3	7	4.2	4	2.4	166	100.0
Physical Exam	104	62.7	55	33.1	4	2.4	3	1.8	166	100.0
Chest X-Ray	60	36.1	84	50.6	13	7.8	9	5.4	166	100.0
ECG	40	24.1	90	54.2	25	15.1	11	6.6	166	100.0
Mammogram	16	9.6	46	27.7	100	60.2	4	2.4	166	100.0
Sigmoidoscopy	3	1.8	70	42.2	81	48.8	12	7.2	166	100.0
PSA	2	1.2	50	30.1	103	62.0	11	6.6	166	100.0
Dental Exam	59	35.5	74	44.6	15	9.0	18	10.0	166	100.0

Percents may not total 100% due to rounding.

In some cases, physician follow-up on exams or screenings was not adequate, as can be noted by reviewing Table 8. One consumer, for example, experienced significant weight loss. Her primary physician neither followed-up on her weight loss nor investigated the cause. Expert panelists indicated that this woman needed a higher level of care to meet her needs for assistance with feeding.

Table 8: Physician Response to Preventive Health Screening Exams and Assessments Findings

	Number Assessed/ Treated	Response Adequate	Response Inadequate	Response Not Rated by Experts
Height/Weight	118	68	22	28
Immunization	82	33	29	20
Vision Screening	121	89	4	28
Hearing Testing	113	78	5	30
Physical Exam	104	58	21	25
Chest X-Ray	60	31	2	27
ECG	40	23	2	15
Mammogram	16	4	2	10
Sigmoidoscopy	3	1	0	2
PSA	2	1	0	1
Dental Exam	59	28	4	26

The expert panelists also rated whether the lack of preventive health screening and assessments contributed to any type of acute health care crisis. The lack of proper screening and assessments did contribute to acute health crisis for 25 (15.1%) consumers (see Table 9).

Table 9: Relationship of Preventive Health Screening and Assessments to Acute Health Crisis by Type of Residence

Health Crisis Related to Lack of Preventive Care	**DC**		**CCF**		**ICF**		**SNF**		**Other CLA**		**Total**	
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	4	22.2	10	18.5	6	13.9	5	11.1	0	0.0	25	15.1
No	12	66.7	19	35.2	22	51.2	20	44.4	3	50.0	76	45.8
Insufficient Documentation	2	11.1	25	46.3	15	34.9	20	44.4	3	50.0	65	39.1
Total	18	100.0	54	100.0	42	100.0	45	99.9	6	100.0	166	100.0

Note: Percents may not total 100% due to rounding. Distribution by living arrangement based on Regional Center Files.

Medical Management of Consumers' Disabilities and Chronic Health Conditions

Using the data documented in consumers' records, expert panelists evaluated how effectively primary care physicians managed consumers' ongoing health care. More than one third of the time panelists indicated that the management of consumers' disabilities and chronic medical problems prevented development of secondary complications (see Table 10). In one case experts wrote in regard to the physician's management, "Exceptional care for multiple problems—outstanding supportive care." This consumer was severely disabled with multiple health problems.

Table 10: Relationship of the Primary Care Physician's Management of the Consumer's Disability or Chronic Medical Conditions to Development of Secondary Complications

Medical Health Care Management Prevented Secondary Complications	DC		CCF		ICF		SNF		Other CLA		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	12	66.7	13	24.1	16	37.2	12	26.7	3	50.0	56	33.7
No	1	5.5	13	24.1	8	18.6	9	20.0	0	0.0	31	18.7
Insufficient Documentation	4	27.8	28	51.8	19	44.2	24	53.3	3	50.0	74	44.6
Total	18	100.0	54	100.0	42	100.0	45	100.0	6	100.0	166	100.0

Note: Percents may not total 100% due to rounding. Distribution by living arrangement based on Regional Center Files.

In other cases consumers weren't so fortunate, and experienced delayed diagnoses, missed diagnoses, and inadequate management of health care (see Table 11). The most common problem noted was "care wasn't aggressive enough." Other problems frequently cited were poor management of aspiration, cardiac problems, dysphagia, general respiratory problems, and inadequate lab work-ups. A consumer, who resided in a CCF, died from acute aspiration pneumonia following a long history of chronic problems with aspiration. Expert panelists indicated that he should have had a swallowing evaluation and been evaluated for GT placement. Another consumer had "ABN [abnormal] swallow study + aspiration NG Dcd [nasogastric tube discontinued]—coded soon after." In another case, female who lived in an ICF/DD was delayed in getting a GT placement. Although she had a history of constipation and GERD (gastroesophageal reflux disease) she did not see a gastroenterologist until after she had a GI (gastrointestinal) bleed. After the placement of a GT tube the consumer was discharged too early, resulting in complications. To make matters worse, in spite of a persistant case of pneumonia, her tube feedings were bolus rather than by an infusion pump. She died from aspiration pneumonia.

Table 11: Ranking of Consumers' Health Problems by Medical Management Issues

	Medical Management Issues			
Health Problems	**Delayed Diagnosis**	**Missed Diagnosis**	**Inadequate Management**	**Total**
	Number	Number	Number	Number
Care Not Aggressive Enough	4	2	8	14
Aspiration	2	4	7	13
Cardiac	3	1	7	11
Dysphagia	1	3	6	10
Respiratory General	2	2	5	9
Inadequate Lab	0	3	6	9
Other GI	2	0	2	4
Cancer	3	1	0	4
Weight	1	1	2	4
Social	1	0	2	3
Seizures	0	0	3	3
GERD	1	0	1	2
Decubiti	1	0	1	2
Diabetes	0	0	2	2
Impactions	1	2	0	3
Urinary	0	0	1	1
Fluid Management	0	0	1	1
Fractures	1	0	0	1
Total	**23**	**19**	**54**	**96**

Expert panelists evaluated consumers' care and identified 79 consumers who would have benefited from referrals to specialists (see Table 12). Forty percent (n=32) of those living in CCFs needed referrals to specialists, as did 30.4% (n=24) of those living in ICFs, and 24.1% (n=19) of those living in SNFs. The referral most likely to be needed was to a clinical nurse specialist, followed by pulmonology, gastroenterology, and cardiology. One consumer with a history of chronic constipation and recurrent impactions was poorly manged by the primary care physician. A referral to a clinical nurse specialist could have helped the facility develop a better program for management of the consumer's ongoing problems with constipation.

Table 12: Referrals That Would Have Improved Health Management for Seventy-Nine Consumers

Type of Referral	Number of Consumers
Clinical Nurse Specialist	38
Pulmonology	20
Gastroenterology	16
Cardiology	15
Nutritionist	12
Psychiatry	10
Neurology	9
Occupational Therapy	9
Pharmacology	8
Endocrinology	8
Speech	8
Dental	8
Orthopedics	5
Physical Therapy	4
Oncology	3
Dermatology	2

A final area of medical management that was reviewed by panelists was management of medications. Medication management was appropriate for the majority of those studied (n=112; 67.5%). As noted on Table 13, inadequate monitoring of medications was the most frequently noted medication management problem. Medication management problems were often linked to overall management issues. CCFs were the most likely type of facility to have this problem, with 20% of their residents needing better medication monitoring, followed by ICFs and SNFs, with about 16% of those from each of these residences needing better medication monitoring.

Table 13: Management of Prescribed Medications by Physician

Observations Of Medication Management	Medication Management by Physician									
	Yes		No		Insufficient Documentation		Not Applicable		Total	
	#	%	#	%	#	%	#	%	#	%
Appropriate	112	67.5	7	4.2	4	2.4	43	25.9	166	100.0
Medication Unmonitored	27	16.3	26	15.7	0	0.0	113	68.1	166	100.0
Over-medicated	9	5.4	27	16.3	3	1.8	127	76.5	166	100.0
Undermedicated	9	5.4	26	15.7	4	2.4	127	76.5	166	100.0
Inappropriately Medicated	9	5.4	21	12.7	5	3.0	131	78.9	166	100.0

Percents may not total 100% due to rounding.

Health Insurance Restrictions

The primary health care insurer for those studied was MediCal (n=134; 80.7%), followed by Medicare (n=24; 14.5%), private insurance (n=2; 1.2%), and "other" (n=5; 3%). Expert panelists noted that insurance restrictions interfered with the delivery of health care for 13 consumers (see Table 14). In one case for example, a consumer with Down syndrome died from cardio pulmonary arrest secondary to a seizure. The expert panelist wrote, "Should have had a neurological workup and consultation with neurologist due to siezure onset at age thirty-four… needed neurological consult and yearly monitoring." The highest number of restrictions occurred for those living in Community Care Facilities.

Table 14: Influence of Health Insurers on the Delivery of Care

Insurance Restrictions Interfered with Health Care Delivery	**DC**		**CCF**		**ICF**		**SNF**		**Other CLA**		**Total**	
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	0	0.0	8	14.8	2	3.7	2	4.5	1	16.7	13	7.8
No	17	94.4	36	66.7	37	86.0	37	82.2	4	66.6	131	78.9
Insufficient Documentation	1	5.6	10	18.5	4	9.3	6	13.3	1	16.7	22	13.3
Total	18	100.0	54	100.0	42	100.0	45	100.0	6	100.0	166	100.0

Percents may not total 100% due to rounding.

Research question 2: Did the quality of health care and supervision provided by residential staffs contribute to the morbidity and/or mortality of individuals studied?

Level of Care

Overall, the majority of consumers were living in residences that provided a level of care appropriate for their health and nursing care needs. Experts indicated that slightly more than one fifth of those residing in CCFs needed a higher level of care (see Table 15).

Table 15: Type of Residence Appropriate for Level of Care Needed

Level of Care Appropriate	DC		CCF		ICF		SNF		Other CLA		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	17	94.4	37	68.5	34	73.1	41	91.1	5	83.3	134	80.7
No	1	5.6	12	22.2	6	13.9	3	6.7	0	0.0	22	13.3
Insufficient Documentation	0	0.0	5	9.3	3	7.0	1	2.2	1	16.7	10	6.0
Total	18	100.0	54	100.0	43	100.0	45	99.9	6	100.0	166	100.0

Percents may not total 100% due to rounding.

As consumers' health care needs changed, only 7 experienced a delay in transfer to another level of care, and two were transferred to levels of care that did not meet their needs. In one case, the provider requested a transfer to a higher level of care because the consumer needed more services than were traditionally provided in an ICF/DD. In order to provide adequately for this consumer the care provider arranged for one-on-one care. She was not funded to support this intense level of service, but was concerned for the consumer's safety as well as the facility's liability.

Residential Facilities' Management of Consumers' Health Problems

More than one half of those studied had care plans in their records. About 45% of all CCF and ICF consumers had care plans (see Table 16). Consumers who had lived in DCs were the most likely to have care plans. Care plans guide daily management of consumers' health needs. They define areas that need to be addressed and how to address them. In addition, they provide information on consumers so all staff know the expected status of consumers' health and needs, and address them in a consistent manner. In some cases consumers with significant health needs lacked care plans. One consumer, for example, had renal insufficiency and COPD, yet there was no plan of care in his record to guide management of his ongoing needs. Another consumer, who died of aspiration pneumonia, did not have a plan addressing dysphagia in spite of chronic problems with aspiration, nor was her weight loss addressed.

Table 16: Care Plans for Management of Consumer's Conditions and Needs by Type of Residence

Care Plans Present	DC		CCF		ICF		SNF		Other CLA		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	15	83.3	24	44.4	20	46.5	24	53.3	3	50.0	86	51.8
No	1	5.5	21	38.9	17	39.5	13	28.9	1	16.7	53	31.9
Insufficient Documentation	2	11.1	9	16.7	6	14.0	8	17.8	2	33.3	27	16.3
Total	18	100.0	54	100.0	43	100.0	45	99.9	6	100.0	166	100.0

When present, care plans were rated regarding their quality (see Table 17). DCs had the highest rated care plans, while 50% of CCF care plans and 37.5% of SNF care plans were rated as less than adequate. Problems with care plan quality included not addressing all health problems, inadequately addressing problems, and inappropriately addressing problems. A consumer with multiple health problems, including heart disease, chronic renal failure, anemia, dysphagia, and congestive heart failure, had an inadequate care plan. Feeding issues were not addressed in the care plan, nor were chronic renal insufficiency, or congestive heart failure. The care plan primarily addressed monitoring intake and output, and treating skin lesions and rashes.

Table 17: Adequacy of Care Plans for Managing Consumers' Needs in Residential Setting

Care Plans Ratings	DC		CCF		ICF		SNF		Other CLA		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
Inadequate/ Min. adequate	0	0.0	12	50.0	7	35.0	9	37.5	2	66.6	30	34.9
Adequate	2	13.3	6	25.0	6	30.0	7	29.1	0	0.0	21	24.4
Very good/ Excellent	12	80.0	6	25.0	6	30.0	7	29.2	1	33.3	31	37.2
Not rated	1	6.7	0	0.0	1	5.0	1	4.2	0	0.0	3	3.5
Total	15	100.0	24	100.0	20	100.0	24	100.0	3	99.9	86	100.0

Percents may not total 100% due to rounding.

Management of the consumers' health by their residential care providers prevented complication in almost 40% of the cases (see Table 18). One individual who resided in a CCF, for example, died from cancer metastasis. Although experts indicated that the medical management of this person's health was poor, the facility was noted to provide a "good death experience" for her. At her request she remained in the CCF, where she received hospice care.

Table 18: Residential Health Care Management Prevented Secondary Complications

Residential Care Prevented Complications	DC		CCF		ICF		SNF		Other CLA		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	14	77.8	14	25.9	17	39.5	16	35.6	2	33.3	63	38.0
No	0	0.0	19	35.2	9	20.9	9	20.0	1	13.7	38	22.9
Insufficient Documentation	4	22.2	21	38.9	17	39.5	20	44.4	3	50.0	65	39.1
Total	18	100.0	54	100.0	43	100.0	45	100.0	6	100.0	166	100.0

Consumers residing in CCFs were the least likely to receive care that prevented secondary complications from developing, with about a quarter of them receiving such care. There was too little documentation to judge the quality of residential care provided to about 40% of the consumers who lived in SNFs, ICFs and CCFs. Inadequate documentation was an issue for a number of consumers regardless of the severity of their health conditions. Ongoing symptoms and care were not described in the record of a consumer dying of cancer metastasis, for example, despite the seriousness of his illness.

To gain insight into the issues related to cases needing improved quality of care, the problems were analyzed to identify the types of health conditions and the types of failures in care. As can be noted on Table 19, the health conditions most likely to be mismanaged, leading to secondary complications, were general respiratory problems, aspiration and recurrent aspiration, dysphagia and seizures. CCFs and ICFs were most likely to have problems managing these health conditions. For example, a CCF resident died from aspiration pneumonia. He had a history of difficulty swallowing fluids, addressed in the plan of care as "feed liquids with a spoon." Experts indicated that this consumer should have had a swallowing evaluation, with follow-up by specialists. Another CCF consumer with a history of fecal impactions and ongoing constipation died secondary to a bowel obstruction. There was no plan of care in this consumer's record to address her chronic constipation and prevent further fecal impactions.

Table 19: Health Conditions Inadequately Managed By Residential Care Facility Staff by Type of Residence

Health Conditions	DC	CCF	ICF	SNF	Other CLA	Total

Respiratory general	0	10	3	4	0	17
Aspiration—recurrent aspiration	1	4	7	1	0	13
Dysphagia	0	5	6	0	0	11
Seizures	0	5	5	1	0	11
Other GI	0	1	3	3	0	7
Decubiti—skin disorder	0	0	3	3	0	6
Social-emotional behavioral	0	2	2	2	0	6
Constipation	0	2	2	0	0	4
GERD	0	2	2	0	0	4
Urinary—renal problems	0	4	0	0	0	4
Fluid management	0	1	2	1	0	4
Total	1	36	35	15	0	87

Inadequate management of the consumers' health problems was most freqeuntly seen as a failure to recognize and respond to health status changes, and a failure to recognize and respond to an emergency (see Table 20). Lack of supervision by an RN, as well as not providing appropriate treatments, and delay in contacting the physician, contributed to adverse health outcomes.

Table 20: Factors That Were Related To Inadequate Management of Health Conditions by Residential Facility Staff

Residential Care Issues	Number of Consumers
Did not recognize or respond to changes in health status	45
Did not recognize emergency illness or health status deterioration	35
Lack of supervision by an RN	22
Did not provide appropriate treatments	22
Delayed contacting physician	20
No documentation of care	14
Did not give medications as prescribed	11
No or limited supportive care	9
Missed physician appointments	8
Did not respond to adverse medication reactions	3
When inconvenient did not provide care to the consumer	3
Known allergy, gave medication	1

In one case, the activity center noticed the consumer was jaundiced, a status change not recognized by the residential staff. This consumer also had a high incidence of falls and seizures, which were not addressed in a care plan. Another consumer became septic, and staff did not recognize the consumer's deteriorating health status until it was advanced. In several other cases family members recognized the consumer's health status changes and contacted consumer physicians themselves. In one case, a consumer died as she was being transported to the physician's office at the insistence of a family

member. Staff did not recognize the seriousness of her illness. Poor communication with physicians also contributed to adverse outcomes.

The level of health care supervision by residential staff was adequate for the majority (51.3%) of consumers (see Table 21). More than one half of the cases of unsafe supervision occurred in CCFs. Most instances of unsafe supervision were related to inadequate protection of consumers from injury during seizures. In most of these cases consumer's seizure activities had increased in frequency without changes in the level of supervision to prevent injury. Care plans often did not adequately address monitoring seizures and protecting consumers from injury. A number of consumers suffered head injuries secondary to lack of adequate safety equipment.

Table 21: Level of Health Care Supervision by Residential Care Facility Staff Appropriate by Type of Residence

Residential Staff Supervised Appropriately	**DC**		**CCF**		**ICF**		**SNF**		**Other CLA**		**Total**	
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	16	88.9	18	33.3	24	55.8	24	53.3	3	50.0	85	51.3
No	0	0.0	11	20.4	4	9.3	3	6.7	0	0.0	18	10.8
Insufficient Documentation	2	11.1	25	46.3	15	34.9	18	40.0	3	50.0	63	38.0
Total	18	100.0	54	100.0	43	100.0	45	100.0	6	100.0	166	100.0

Less than 5% of the cases were noted to live in an unsafe environment (See Table 22). Lack of documentation prevented an assessment of 40% of those living in SNFs, and almost 50% of those living in CCFs.

Table 22: Residential Health Care Staff Provided a Safe Environment

Residential Environment Safe	**DC**		**CCF**		**ICF**		**SNF**		**Other CLA**		**Total**	
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	16	88.9	25	46.3	27	62.8	25	55.6	3	50.0	96	57.8

No	0	0.0	3	5.6	3	7.0	2	4.4	0	0.0	8	4.8
Insufficient Documentation	2	11.1	26	48.1	13	30.2	18	40.0	3	50.0	62	37.4
Total	18	100.0	54	100.0	43	100.0	45	100.0	6	100.0	166	100.0

Slightly more than one half of the consumers studied needed emergency care at the time of deaths (See Table 23). About 80% of those residing in ICFs needed emergency care. Far fewer residing in SNFs needed such care, which is to be expected since SNFs provide care for terminally ill individuals.

Table 23: Need for Emergency Care by Type of Residence

Emergency Care Needed	**DC**		**CCF**		**ICF**		**SNF**		**Other CLA**		**Total**	
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	9	50.0	29	53.7	34	79.1	14	31.1	3	50.0	89	53.6
No	6	33.3	12	22.2	8	18.6	24	53.3	2	33.3	52	31.3
Insufficient Documentation	3	16.7	13	24.1	1	2.3	7	15.6	1	16.7	20	12.0
Total	18	100.0	54	100.0	43	100.0	45	100.0	6	100.0	166	99.9

Percents may not total 100% due to rounding.

In less than 15% of cases emergency care was judged to not be appropriate. In some of these cases Advanced Care Directives were not followed and emergency treatment was initiated in violation of the directive. In one such case the facility staff indicated that as a CCF they were required to initiate emergency treatment in spite of Advanced Care Directives. In another case, treatment was initiated on an individual who had been dead for more than 2 hours. In other cases Advanced Care Directives had not been obtained and emergency care was initiated when the consumer was clearly terminal.

Table 24: Emergency Care Appropriate by Type of Residence

Emergency Care Appropriate	**DC**		**CCF**		**ICF**		**SNF**		**Other CLA**		**Total**	
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	8	44.4	18	33.3	24	55.8	15	33.3	3	50.0	68	40.9
No	1	5.6	11	20.4	8	18.6	4	8.9	0	0.0	24	14.5
Insufficient Documentation	3	16.7	10	18.5	1	2.3	9	20.0	1	16.7	24	14.5
Not Applicable	6	33.3	15	27.8	10	23.3	17	37.8	2	33.3	50	30.1
Total	18	100.0	54	100.0	43	100.0	45	100.0	6	100.0	166	100.0

Research Question 5: Did the consumer's or family member's wishes contribute to morbidity or mortality?

Only 4 consumers developed serious health problems secondary to their refusal to cooperate with their health care regime (see Table 25). In one case a consumer refused a simple life-saving procedure. Expert panelists questioned whether the consumer, who was mentally retarded, was appropriately counseled. In another case the consumer's use of alcohol, cigarettes, and street drugs contributed to his death. Again, the question was raised about the quality of education offered to the consumer. Were educational approaches adapted to the unique learning needs of this individual?

Table 25: Consumer Refusal to Cooperate With Needed Care or Treatment by Type of Residence

Consumer Refused Care or Treatment	DC		CCF		ICF		SNF		Other CLA		Total	
	#	%	#	%	#	%	#	%	#	%	#	%
Yes	1	5.6	2	3.7	0	0.0	1	22.2	0	0.0	4	2.4
No	15	83.3	42	77.8	40	93.0	37	82.2	5	83.3	139	83.7
Insufficient Documentation	1	5.6	7	13.0	2	4.7	7	15.6	1	16.7	18	10.8
Not Applicable	1	5.6	3	5.6	1	2.3	0	0.0	0	0.0	5	3.0
Total	18	100.0	54	100.0	43	100.0	45	100.0	6	100.0	166	99.9

In four other cases family members' choices regarding medical management and follow-up contribued to the consumer's death.

Research Question 5: Did the consumer engage in criminal activity that contributed to their death?

There were no cases where consumer's participation in criminal activities contributed to their deaths.

Statistical Analysis

Overall, there were few statistically significant differences in the quality of care provided by the differenct types of facilities, with the exception being care provided in DCs (see Table 26 below). A higher quality of care was provided at DC's, a finding consistent with the prior mortality study. However, findings in this study are probably not meaningful since the sample of cases from DCs (n=18) was so small.

Table: 26 Mann-Whitney Test P-values for comparing quality of care ratings by Living Status

Variables	DC vs. SNF	DC vs. CCF	DC Vs. ICF	DC Vs. Other	SNF vs. CCF	SNF vs. ICF	SNF vs. Other	CCF vs. ICF	CCF vs. Other	ICF vs. Other
Lack of preventive screening contributed to illness	.015	.037	.077	.077	.818	.371	.679	.531	.622	.394
Medical management did not prevent secondary complications	.017	.013	.074	.494	.974	.407	.666	.389	.657	.894
Health insurance restrictions adversely affected care	.716	.693	.943	.871	.399	.608	.787	.655	1.00	.894
Lack of residential health care plan	.048	.012	.022	.251	.508	.735	.700	.749	.876	.778
Level of primary residence not appropriate	.855	.034	.134	.673	.003	.050	.673	.339	.705	.941
Not transferred to a higher level of care as needs changed	.736	.217	.067	.391	.196	.034	.263	.379	.098	.044
Residential care management did not prevent secondary complications	.016	.004	.024	.156	.742	.809	.778	.541	.541	.710
Levels of residential staff supervision not adequate	.014	.000	.024	.177	.175	.717	.760	.075	.852	.659
Residential staff did not provide a safe environment	.019	.004	.065	.177	.472	.408	.738	.114	.949	.493

DISCUSSION AND RECOMMENDATIONS

This study was a follow-up to a previous study of deaths of individuals with developmental disabilities who died in 1994. Findings from the first study demonstrated the importance of examining the influence of the quality of health care on consumer morbidity as well as on consumer mortality. As in the first study, we collected detailed data on the types of health-care related services received by consumers in various kinds of settings. This study differs from the prior one in that we used expert panelists from California rather than from across the country to rate the quality of health care for the sample of persons who had died. There were several advantages to this approach. These experts were all familiar with the Regional Center system and available resources. Pulling the experts together as a group allowed discussion of ratings that had not been possible with the prior study; these discussions eliminated differences in ratings across experts. Using comments made by expert panelists in the first study we refined the expert panelist form, ensuring consistent documentation of the types of health care problems and care issues related to the cases. In addition, we were also able to review initial findings with these California-based experts and obtain their interpretation of the data and comments on the implications of the findings. They were also able to offer

some suggestions for improving the way services are delivered in order to prevent adverse consumer outcomes.

Documentation of Care

Before discussing the findings related to the study's research questions, we must point out that the most consistent finding in this study, as in the prior study, was insufficient documentation of care. Many aspects of what had occurred with the consumer and his or her health care simply were not available in any of the written records. The Expert Panelists were unable to comment on the quality of care for about 40% of cases they reviewed. This was particularly pertinent for their ratings in the following key areas:

- Contribution of lack of preventive health screening and assessments to the acute health crisis (65; 39.1%);
- Physician management of consumer's disability or chronic medical conditions prevented secondary complications (74; 44.6%);
- Residential facility management of consumer's disability or chronic medical conditions prevented secondary complications (65; 39.1%).

The lack of documentation was an issue in each type of facility, the exception being DCs. Three of the DC cases that lacked adequate documentation were consumers who had recently been transferred to the DC.

The quality of documentation was not related to the seriousness of the consumer's health status. One client had brain surgery, but there was no information regarding why. Another client was immune suppressed but the record did not indicate why. People are living longer now in spite of serious health problems. It is important to know something about their original health problems. A clear historical summary of health status is needed. Large files are purged and important data regarding immunizations and lab values may be lost. An additional complication is the number of agencies serving the population, such as Regional Centers, Health Management Organizations, schools, California Children's Services and Mental Health. Each agency has its own record and may not be keeping other agencies apprised of the person's health status. This is further complicated when residential facilities do not

maintain adequate data on consumers' health status, results of medical office visits, test results, and documentation of medications administered.

Recommendations to resolve these issues are as follows:

- Develop a central database that documents key health data, including history and progress.
- The data from this database should follow the consumers wherever they reside—"portability" of health data is essential for those with chronic, multiple health problems.
- Maintain old medical files for consumers as part of their Regional Center record. Don't purge key medical information. Keep a "stable events" cover sheet in their file that contains significant lab results, surgical events, medications and so forth.
- Greater Regional Center oversight and input is needed into care and record keeping for consumers in out-of-home placements.
- Regulations should require forms documenting medications given—dosage, why given, when started and when stopped--for all facilities, including CCFs, even if this requires a change in regulations.
- Pharmacists should review medications quarterly.
- Each Regional Center should have medical records staff who follow standardized, uniform record protocols. Their responsibilities should include working with insurance agencies and health care providers to obtain key health data, and ensuring that an accurate record of the consumers' medical conditions is maintained.
- Regional Centers should notify/share records, including a copy of the annual review, with the primary care physician.

Research Question 1: Did the quality of health care services provided by the community health care delivery system (including physicians and health insurers) contribute to the morbidity and/or mortality of individuals studied?

Preventive Health Care Screening Exams and Assessments

Preventive health care screening exams and assessments were inconsistently provided to the population studied. Although most consumers had some immunizations recorded, the list for 73 consumers (44%) was incomplete. Records were often out-of-date. Influenza vaccinations, for example, were not recorded in recent years. Panelists also cited the absence of vaccinations for pneumonia. Consumers with significant symptoms, including recurrent pneumonia and persistent coughs, lacked documentation of chest x-rays. Baseline ECGs were obtained for some consumers as they entered into old age, while others not only lacked this basic test but also had cardiac symptoms that were not fully assessed. In some cases panelists indicated that tests were probably missing due to the difficulty of conducting the exams for individuals with severe physical limitations or behavioral problems. Institutions using traditional equipment and staff untrained in working with this high-risk population may not be able to adapt to their special needs.

Another key issue is "consumer choices" regarding life style. There is a tendency to state that a person has a right to life style choices without seriously examining how effectively the options for healthier life styles were presented. Health education approaches must accommodate the developmental status of the consumer. Traditional health education approaches are not appropriate for this population.

The following recommendations address needed improvements to promote preventive health education and assessments for those with developmental disabilities:

- Regional Centers should adopt the USPHS health standards for preventive health care and screening, adjusted for the consumer population, and distribute the guidelines to providers.
- There needs to be an increasing emphasis on health promotion.
- Education approaches that are sensitive to the developmental status of consumers should be promoted and developed; improved education strategies, such as smoking clinics designed for Regional Center consumers need to be developed.
- DDS should increase linkages between the Regional Centers and DCs—The DCs are specially equipped to provide exams for Regional Center clients. Dental exams, and treatment, swallowing studies, durable medical equipment

prescriptions, and the development of client-specific care plans are some of the many services they could offer to this population.

- DCs should publish the services they provide and DDS needs to establish billing and other mechanisms to encourage and facilitate use of DC expertise and services by Regional Center consumers.

Managing Consumer Disabilities and Chronic Health Problems to Prevent Secondary Complications

Individuals with developmental disabilities tend to have more complex and persistent health problems than other populations. Consumers who have multiple, chronic, health problems need to have well-managed health care. Expert panelists indicated that too often consumers received episodic care; they needed better management of their ongoing health problems, both by their medical providers and by the residential care facility staff.

The health conditions most likely to be mismanaged by health care providers are common to this population. They include aspiration, dysphagia, general respiratory problems, and cardiac conditions. Care of those with disabilities needs to be as aggressive as the care provided to those without disabilities. More referrals to specialists with expertise in serving this population were needed by 79 of the 166 consumers studied. Inadequate access to specialists adversely affected the health status of these consumers. The most frequently cited type of referral needed was to a clinical nurse specialist, followed by pulmonology, gastroenterology, and cardiology. The types of specialists needed were consistent with the types of health problems identified by expert panelists.

Management of medications was a problem for 54 consumers, with inadequate monitoring of medications being the most likely problem. This was an issue in all types of facilities, with the exception of DCs.

In order to improve outcomes the expert panelists recommended that a health care "crib book" be developed for community physicians on managing conditions commonly found in the Regional Center populations. This crib book should include the following:

- Guidelines for ongoing medical management of dysphagia, aspiration, respiratory problems, constipation, and cardiac conditions; guidelines should address the interplay of these conditions, since many consumers have multiple, chronic health conditions that are often related to their developmental status;
- Information on the types of specialists needed by consumers with these conditions, as well as criteria for when referrals should occur;
- Guidelines for medication management of common conditions, including monitoring drugs;
- Criteria for when Regional Center case managers and residential facilities need to call in a Regional Center physician or nurse for consultation should be developed and published.

In addition, Regional Center medical and nursing staff services should be used to more closely monitor the health care services provided to the population they serve. Better documentation of ongoing medical care is necessary for Regional Centers to provide this monitoring and oversight.

Insurance restrictions were an issue for 13 individuals studied. This is an increase from the previous study. Regional Center staffs need to be cognizant of the potential for denial of needed services, especially for those residing in CCFs, so that they can intervene when such restrictions occur. Advocacy is needed for this population to ensure that their right to health care services is respected. This is particularly true as resources for health care become more limited.

Research Question 2: Did the quality of health care and supervision provided by residential staffs contribute to the morbidity and/or mortality of individuals studied?

Managing Consumer Health Problems to Prevent Secondary Complications

The major issue related to residential facility services is inadequate management of consumers' ongoing health problems. Health problems most frequently noted to be inadequately managed were dysphagia, aspiration, general respiratory problems, and seizures. This was consistent with findings from the 1994 study.

The most serious breakdown in residential care management was a lack of timely recognition of illnesses & deterioration in health status. This failure generally resulted in delayed contact of physicians and serious exacerbation of health problems. Experts indicated that lack of oversight by RNs contributed to this failure as well as other health management problems. Treatments and medications were not given appropriately. Consumers with seizures suffered head injuries due to lack of safety equipment. In many cases, residential health care, including patient problems, responses to interventions, ongoing health status, and the results of medical visits, were not documented in consumer records.

The consumer health problems identified by expert panelists are common to this population. In fact, they are the same health care problems physicians need guidelines for – a key difference being that guidelines for residential care must focus on day-to-day management of the consumer's needs. Standardized care plans that carefully delineate daily care to treat ongoing health problems and define activities to prevent secondary complications from developing need to be adopted. They can then be tailored for each client's specific needs.

Findings from this study indicate greater use of care plans by residential facilities than found previously. Care plans were present in more than one half of consumers' records. Significant improvements were made in the presence of care plans for CCFs since the last study. In this study, 44.4% of CCFs had care plans in consumer records compared to 16% in the study of 1994 deaths. Unfortunately, the adequacy of care plans has decreased across the board for community residential facilities from the 1994 study. Ratings of "inadequate" or "minimally adequate" for CCF, ICF and SNF care plans ranged from 35% to 50%. In the 1994 study the range was from 6.3% to 12.2%.

The following recommendations, suggested by expert panelists, could help improve ongoing health care provided in residential facilities:

- Develop standardized care plans for residential facilities focusing on care management of health conditions commonly found in the Regional Center population. This should include management of dysphagia, aspiration, respiratory problems, constipation, and seizures, as well as other health problems common to the population.

- Regional Centers need to provide sample care plans for residential facilities. Ratings for the quality of DC care plans were very high in both studies. The expertise of those working in DCs needs to be more available to community residential facilities. Their standardized care plans should be published for use by community-based facilities. Additionally, a mechanism should be developed for Regional Centers and residential facilities to access the expertise of DC staff when planning the care of consumers with complex health problems. Finally, those Regional Centers that have developed standardized care plans need to publish their plans for use by other Regional Centers.
- Establish and enforce a level of documentation of ongoing health status, residential care, and physician services that allows oversight of consumer health care by registered nurses.
- Develop and publish criteria for when Regional Center case managers and residential facilities need to call in a Regional Center nurse for consultation.

Emergency Responses

Emergency response at the time of death was found to be appropriate for the majority of consumers. On the other hand, those for whom emergency responses were not suitable were often given emergency treatments when they clearly weren't needed. Generally, this occurred when the individual had a terminal illness or was at the end of his or her life. Since the population served by Regional Centers is aging there needs to be greater attention to "end of life" issues. A number of consumers have survived for many years, and are now entering the last stages of life. Advanced Care Directives need to be considered for a number of these consumers. The following recommendations address this issue:

- Clear guidelines for Advanced Care Directives need to be developed for Regional Centers and adopted universally.

- DCs have guidelines for Advanced Care Directives and these should be shared with all Regional Centers again.
- Hospice services should be considered for all Regional Center consumers who have a terminal health condition—even if they are in a residential program.

Research Question 3: Did the consumer's or family member's wishes contribute to morbidity or mortality?

In a few cases consumer lifestyle choices were directly related to the cause of death. As noted previously, serious attention needs to be focused on the issue of life style choices. Critical to this topic is the issue of "informed consent." Are consumers adequately informed of the consequences of their choices? Are they offered education adapted to their unique learning needs? Are they adequately motivated to try healthier life styles? Attention needs to be paid to their role models in residential facilities. Are staff, for example, smoking in front of consumers? This key area needs to be addressed as part of a preventive health promotion program for consumers served in the Regional Center system. This is particularly important now that the population is aging.

Research Questions 4: Did the consumer engage in criminal activity that contributed to their death?

This was not an issue for any consumers in this sample.

Limitations and Strengths of the Study

It was hoped that accessing data within a year or two of the death would increase availability of records. As in the 1994 study, some data were destroyed or lost. Some facilities refused to cooperate because of issues related to consumer deaths, and other data were unavailable because of pending legal actions. Findings were limited to data available, and in some instances, documentation on consumer care was minimal. Although some hospital data were accessed, physician office records were not accessible.

This study also has limited generalizability because of sampling issues. The intent was to draw a random sample of 200 from among the 739 persons who died in the first half of 1999 while living in out-of-home settings. Unfortunately, a number of persons who lived with their families or in independent living settings were inadvertently included in the sample, as well as a few persons who actually died in 1998. Because of these issues, only 166 persons were included in the sample. This could have influenced the generalizability of the findings. However, the consistency of the results of this study in comparison to the 1994 study suggests that these findings are substantial and meaningful.

A strength was that a panel of expert physicians and nurses who practice within California was selected and brought together to review study findings. They were able to dialogue with one another regarding their points-of-view. Although the research team anticipated some cases where the experts might not agree about findings, there was complete agreement among the physician-nurse teams. This demonstrated that the problems identified were straightforward variations from expected practice. There was a breakdown in management of health problems common to those with developmental disabilities. Physicians and residential facilities had difficulties managing the same kinds of health problems.

This study also offered the opportunity for outstanding experts to discuss treatment approaches and health care issues. Their familiarity with the California system provided them with the expertise to suggest viable methods to improve the overall system of health service delivery. Examining the influence of care on consumer outcomes provides important insight into factors that contribute to morbidity and mortality among those served by DDS. Consumers' developmental characteristics influence the types of health problems they develop and the types of residential facilities within which they reside. The quality of health services, however, influence how well predictable health problems are treated and adverse outcomes are prevented. Review of morbidity as well as mortality offers the opportunity to focus education and monitoring approaches on those problems most common to the population.

Summary

This follow-up study demonstrates that there have been improvements in the quality of health care for individuals with developmental disabilities since the last study, which examined deaths that occurred in 1994. Proportionately fewer individuals were noted to have problems with physician and residential staff management of their ongoing health problems. However, the quality of health care, including supervision and treatment, continues to be an issue for those who reside in out-of-home settings. Increased oversight of health care management by Regional Center staffs is needed to ensure adequate health care for those living in residential facilities. Priority should be given to addressing the health problems identified in this study, which are consistent with those identified in the study of 1994 deaths—dysphagia, aspiration, respiratory problems, GERD and other GI problems, cardiac problems, and seizures. Better management of these specific conditions by physicians and residential facility staff can result in significant improvements in consumers' health status.

Another area that needs to be addressed is health promotion. More emphasis is needed to ensure those with disabilities receive the preventive health screening tests and examination recommended for the general population. Simple measures, such as publishing standards and documenting tests and their results, can result in immediate improvements in these services. There are a number of models for monitoring preventive health exams used by managed health care organizations that could be adapted for use by Regional Centers. A more complex issue is increasing access of those with developmental disabilities to the specialty services offered in DCs. Fiscal barriers to accessing DC services need to be resolved so that those residing in other types of community settings can benefit from the outstanding expertise available through the California DCs.

Inadequate documentation of services continues to be a critical problem for those who reside in out-of-home community-based facilities. The staffs at residential facilities are held accountable, under regulation, for consumer health outcomes. They are, therefore, given the option of selecting which physicians consumers are seen by (unless family or consumers request a different provider). They become a type of gatekeeper who selects the physicians, including specialists and, in some cases, types of specialists, who care for consumers residing in their facilities. Thus, residential facilities are the agencies that can most readily document consumer health services.

They are in the best position of any agency to maintain files documenting services consumers received, as well as the results of those services. Residential facilities should be required to maintain this data and share it with the Regional Center as part of the consumer's annual review.

Individuals with developmental disabilities tend to have multiple, chronic health problems. They are dependent on their caregivers to help them address these problems. Documentation is key to monitoring responses to treatments and interventions, as well as changes in health status. Without documentation, care is dependent on the accuracy of care provider's memories as well as communication between staffs. When considering the seriousness of the health conditions of the consumers, this is not an adequate method for health care management. Residential facilities need to document care and have functional care plans. Regional Center staff can provide assistance in care planning and oversight of health care. The Regional Center should add relevant health history data to the consumer's record on an annual basis, using documentation supplied by the residential facility.

Finally, this study allowed the opportunity to evaluate the quality of care provided to a sample of consumers who died in 1999. The expert panelists who reviewed consumer records provided valuable insight into methods of improving health care management for those with disabilities. Bringing an interdisciplinary panel of experts together to examine health outcomes is a valuable method of identifying trends and patterns in health care delivery for this population. In addition, these outstanding experts can offer practical suggestions for improving the way services are structured, offered and monitored. Their expertise should be used to develop "crib books" for community physicians and residential facilities. They should also review and critique standardized care plans. Finally, their expertise should be sought on an ongoing basis to identify and interpret trends and patterns in consumers' health status and the delivery of health care.

APPENDIX

EXPERT PANEL CODING FORM

1. **Reviewer:**
2. **Case Number:**

3. MD's & FNP's Based on available data, what was the presumptive cause(s) of death?

_____

_____

Part I: Services Provided By Community Health Care Delivery System

A. Rate documentation of health care in the record:

[ ] 1= Sufficient, 2= Insufficient, 3= No documentation

B. Given the condition and age of the client, were preventive care screening exams and assessments adequate (See: annual physical exam, lab, and x-ray)?

Complete the following:	**Assessment Done**			**Adequate Response**		
Screening exams	**1=Yes**	**2=No**	**3=NA**	**1=Yes**	**2=No**	**3=NA**
1. Height & weight	1	2	3	1	2	3
2. General condition /appearance	1	2	3	1	2	3
3. Immunizations & vaccinations	1	2	3	1	2	3
4. Vision screening	1	2	3	1	2	3
5. Hearing screening	1	2	3	1	2	3
6. PE	1	2	3	1	2	3
Screening lab & x-rays						
7. Chest x-ray	1	2	3	1	2	3
8. ECG	1	2	3	1	2	3
9. Mammogram	1	2	3	1	2	3
10. Sigmoidoscopy	1	2	3	1	2	3
11. PSA	1	2	3	1	2	3
12. Pap smear	1	2	3	1	2	3
13. Annual dental exam	1	2	3	1	2	3
14. Other specify	1	2	3	1	2	3
15. Other specify	1	2	3	1	2	3

C. Did lack of preventive screening and follow-up assessments contribute to an acute health care crisis?

[ ] 1=Yes, 2=No, 3= Insufficient Documentation

Comment:

_____

_____

D. Was the management of the consumer's health care by his/her physicians appropriate?

[ ] 1= Yes, 2 = No, 3 = Insufficient Documentation

Comment:

_____

E. Did the management of the disability or chronic medical condition prevent secondary complications? [ ] 1=Yes, 2=No, 3= Insufficient Documentation

Of the medical conditions present in this case, please indicate whether there was Delayed Treatment, Missed Diagnosis, or Inadequate Management for any of the person's health conditions using the following table: **(check all that apply)**

CONDITIONS	DELAYED (DX)	MISSED (DX)	INADEQUATE MANAGEMENT	SPECIFY
1. DYSPHAGIA				
2. CONSTIPATION				
3. OTHER GI PROBLEMS				
4. GERD				
5. ASPIRATION/ RECURRENT ASPIRATION				
6. RESPIRATORY GENERAL				
7. URINARY/RENAL PROBLEMS				
8. FLUID MANAGEMENT				
9. DECUBITI/OTHER SKIN DISORDER				
10. SOCIAL/ EMOTIONAL BEHAVIORAL				

CONDITIONS	DELAYED (DX)	MISSED (DX)	INADEQUATE MANAGEMENT	SPECIFY
11. SEIZURES				
12. DIABETES/ OTHER ENDOCRINOLOGICAL PROBLEM				
13. CANCER				
14. FRACTURES/ INJURY				
15. ADVERSE MEDICATION REACTION				
16. WEIGHT CHANGE				
17. INADEQUATE LAB OR X-RAY				
18. CARE NOT AGGRESSIVE ENOUGH				
19. CARDIAC				
(A) HIGH BLOOD PRES.				
(B) ARRTHYMIAS				
20. OTHER/SPECIFY				
21. OTHER/SPECIFY				

Commentary: Please state your recommendations for needed additional care.

_____

_____

Would referrals to any of the following have improved health management? (Check)

	YES	NO

1. CLINICAL NURSE SPECIALIST	[ ]	[ ]
2. CARDIOLOGY	[ ]	[ ]
3. DENTAL	[ ]	[ ]
4. DERMATOLOGY	[ ]	[ ]
5. ENDOCRINOLOGY	[ ]	[ ]
6. NEUROLOGY	[ ]	[ ]
7. NUTRITIONIST	[ ]	[ ]
8. OCCUPATIONAL THERAPY	[ ]	[ ]
9. ORTHOPEDICS	[ ]	[ ]
10. PHARMACOLOGY	[ ]	[ ]
11. PHYSICAL THERAPY	[ ]	[ ]
12. GASTROENTEROLOGY	[ ]	[ ]
13. PSYCHIATRY	[ ]	[ ]
14. PULMONOLOGY	[ ]	[ ]
15. SPEECH/AUDIOLOGY	[ ]	[ ]
16. ONCOLOGY	[ ]	[ ]
17. OTHER/SPECIFY	[ ]	[ ]

Indicate Observations Regarding Prescribed Medications			
	1=Yes	**2= No**	**3= NA**
1. Appropriate	1	2	3
2. Over-medicated	1	2	3
3. Medications not monitored	1	2	3
4. Under-medicated	1	2	3
5 Inappropriate medication prescribed	1	2	3
6. Other, specify:	1	2	3

Commments on Medication Management:

_____

_____

G. Health insurance restrictions interferred with the delivery of appropriate care?

[ ] 1=Yes, 2=No, 3= Insufficient Documentation

Part II: Residential Provider Services

1. Were there health care plans for the day-to-day management of the consumer's conditions and needs?

[ ] 1= Yes, 2=No, 3= Insufficient Documentation

Comments**:**

_____

2. If YES (No. 1), how would you rate the adequacy of the care plans for meeting the consumer's needs?

[ ] 1=Inadequate, 2=Minimally adequate, 3=Adequate, 4=Very good, 5=Excellent

Comments:_____

3. The level(s) of care of the primary residence was appropriate for the consumer's medical/nursing needs and conditions.

[ ] 1=Yes, 2=No, 3= Insufficient Documentation

4. If the consumer's medical/nursing needs and conditions changed, was the consumer transferred to the appropriate level of care?

[ ] 1= Transfer not needed, 2=Transfer delayed, 3=Transfer appropriate, 4= Transfer did not meet level of care needed

5. Did the management of the consumer's health by their residential care providers prevent secondary complications?

[ ] 1=Yes, 2=No, 3= Insufficient Documentation

Instructions: If any of the following conditions existed, using the numerical code on the right side of the table, please indicate the residential care problems:

CONDITIONS	PROBLEMS				CODES FOR PROBLEMS	
1. DYSPHAGIA					**1**	No docmentation

2. CONSTIPATION					**2**	Known allergy/gave medication
3. OTHER GI PROBLEMS					**3**	Did not give medications as prescribed
4. GERD					**4**	Did not respond to adverse medication reactions
5. ASPIRATION- RECURRENT ASPIRATION					**5**	Missed MD appointments
6. RESPIRATORY GENERAL					**6**	Delayed contacting MD
7. URINARY- RENAL PROBLEMS					**7**	No or limited supportive care
8. FLUID MANAGEMENT					**8**	Did not recognize or respond to changes in health status
9.DECUBITI- SKIN DISORDER					**9**	Did not recognize emergency illness or health status deterioration
10. SOCIAL- EMOTIONAL BEHAVIORAL					**10**	Lack of supervision by RN
11. SEIZURES					**11**	Did not provide appropriate treatments
12. OTHER SPECIFY					**12**	When inconvenient did not provide care to consumer
13. OTHER SPECIFY						

7. Did residential staff provide appropriate supervision?

[ ] 1=Yes, 2=No, 3= Insufficient Documentation

8. Did residential staff provide a safe environment?

[ ] 1=Yes, 2=No, 3= Insufficient Documentation

Comments (7 and 8):_____

_____

PART III: Emergency Response

1. Was emergency care/response needed?

[ ] 1=Yes, 2=No, 3= Insufficient Documentation

2. Did residential staff provide appropriate emergency response care?

[ ] 1=Yes, 2=No, 3= Insufficient Documentation

PART IV: Consumer

1. The consumer's refusal to cooperate with health care or treatment recommendations contributes to their death.

[ ] 1=Yes, 2=No, 3= Insufficient Documentation

2. The consumer's lifestyle and behavioral choices contribute to death.

[ ] 1=Yes, 2=No, 3= Insufficient Documentation

3. Criminal activity by the consumer contributes to death.

[ ] 1=Yes, 2=No, 3= Insufficient Documentation

4. Family and/or guardian choices regarding the medical management follow-up, hospitalization, or treatment contributes to the consumer's death.

[ ] 1=Yes, 2=No, 3= Insufficient Documentation